# **Complete Summary**

#### **GUIDELINE TITLE**

EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force.

# **BIBLIOGRAPHIC SOURCE(S)**

Farbu E, Gilhus NE, Barnes MP, Borg K, de Visser M, Driessen A, Howard R, Nollet F, Opara J, Stalberg E. EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force. Eur J Neurol 2006 Aug;13(8):795-801. [80 references] PubMed

#### **GUIDELINE STATUS**

This is the current release of the guideline.

There are ongoing studies evaluating the effect of immune modulating therapy in post-polio syndrome (PPS). The results will probably be ready within the next 2 years. A revision of these guidelines would be useful at the same time.

## **COMPLETE SUMMARY CONTENT**

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IDENTIFYING INFORMATION AND AVAILABILITY

**DISCLAIMER** 

# **SCOPE**

## DISEASE/CONDITION(S)

Post-polio syndrome (PPS)

## **GUIDELINE CATEGORY**

Diagnosis Management Rehabilitation Treatment

## **CLINICAL SPECIALTY**

Family Practice Internal Medicine Neurology Physical Medicine and Rehabilitation

#### **INTENDED USERS**

Physical Therapists Physicians Respiratory Care Practitioners

## **GUIDELINE OBJECTIVE(S)**

To develop a common definition of post-polio syndrome (PPS) and evaluate the existing evidence for the clinical effectiveness of therapeutic interventions and on this basis provide clinical guidelines for management of PPS

## **TARGET POPULATION**

Patients with post-polio syndrome (PPS)

# INTERVENTIONS AND PRACTICES CONSIDERED

# **Diagnosis**

Assessing symptoms and ruling out all other possible causes of new symptoms

# **Treatment/Management**

- 1. Supervised muscular training (isokinetic and isometric)
- 2. Training in a warm climate, non-swimming water exercises
- 3. Respiratory muscle training
- 4. Group training, regular follow-up, and patient education
- 5. Weight loss
- 6. Use of properly fitted assistive devices

**Note**: Pyridostigmine, steroids, and amantadine were considered but not recommended because of lack of therapeutic effect.

## **MAJOR OUTCOMES CONSIDERED**

Effectiveness of treatment in improving muscle strength and cardiovascular fitness and reducing pain

#### **METHODOLOGY**

# METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

# DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Medline via Pubmed, EMBASE, ISI and the Cochrane Library were searched from 1966 to 2004. Search terms were PPS/post-poliomyelitis/PPMA/PPMD/poliomyelitis in combination with management, therapy, treatment, medicaments, physiotherapy and intervention.

No meta-analyses of interventions for post-polio syndrome (PPS) were found when searching the databases.

#### NUMBER OF SOURCE DOCUMENTS

Not stated

# METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

## RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

## **Evidence Classification Scheme for a Diagnostic Measure**

**Class I**: A prospective study in a broad spectrum of persons with the suspected condition, using a "gold standard" for case definition, where the test is applied in a blinded evaluation, and enabling the assessment of appropriate tests of diagnostic accuracy

**Class II**: A prospective study of a narrow spectrum of persons with the suspected condition, or a well-designed retrospective study of a broad spectrum of persons with an established condition (by "gold standard") compared to a broad spectrum of controls, where test is applied in a blinded evaluation, and enabling the assessment of appropriate tests of diagnostic accuracy

**Class III**: Evidence provided by a retrospective study where either persons with the established condition or controls are of a narrow spectrum, and where test is applied in a blinded evaluation

**Class IV**: Any design where test is not applied in blinded evaluation OR evidence provided by expert opinion alone or in descriptive case series (without controls)

## **Evidence Classification Scheme for a Therapeutic Intervention**

**Class I**: An adequately powered prospective, randomized, controlled clinical trial with masked outcome assessment in a representative population or an adequately powered systematic review of prospective randomized controlled clinical trials with masked outcome assessment in representative populations. The following are required:

- a. Randomization concealment
- b. Primary outcome(s) is/are clearly defined
- c. Exclusion/inclusion criteria are clearly defined
- d. Adequate accounting for dropouts and crossovers with numbers sufficiently low to have minimal potential for bias
- e. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences

**Class II**: Prospective matched-group cohort study in a representative population with masked outcome assessment that meets a-e above or a randomized, controlled trial in a representative population that lacks one criteria a-e

**Class III**: All other controlled trials (including well-defined natural history controls or patients serving as own controls) in a representative population, where outcome assessment is independent of patient treatment

**Class IV**: Evidence from uncontrolled studies, case series, case reports, or expert opinion

#### METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review

## **DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE**

Not stated

#### METHODS USED TO FORMULATE THE RECOMMENDATIONS

**Expert Consensus** 

# DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Data were classified according to their scientific level of evidence as class I–IV. Recommendations are given as level A–C according to the scheme for European Federation of Neurological Societies (EFNS) guidelines (see the "Availability of Companion Documents" field in this summary). When only class IV evidence was available but consensus could be reached the Task Force gives recommendations as good practice points. Consensus was reached mainly through e-mail correspondence.

A questionnaire about diagnosis, management and care of post-polio patients was answered by the group members from the Netherlands, Norway, Poland, Sweden, and UK.

#### RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

## Rating of Recommendations for a Diagnostic Measure

**Level A rating** (established as useful/predictive or not useful/predictive) requires at least one convincing class I study or at least two consistent, convincing class II studies.

**Level B rating** (established as probably useful/predictive or not useful/predictive) requires at least one convincing class II study or overwhelming class III evidence.

**Level C rating** (established as possibly useful/predictive or not useful/predictive) requires at least two convincing class III studies.

# Rating of Recommendations for a Therapeutic Intervention

**Level A rating** (established as effective, ineffective, or harmful) requires at least one convincing class I study or at least two consistent, convincing class II studies.

**Level B rating** (probably effective, ineffective, or harmful) requires at least one convincing class II study or overwhelming class III evidence.

**Level C rating** (possibly effective, ineffective, or harmful) requires at least two convincing class III studies.

**Good Practice Points** When only class IV evidence was available but consensus could be reached the Task Force gives recommendations as good practice points.

## **COST ANALYSIS**

A formal cost analysis was not performed and published cost analyses were not reviewed.

#### METHOD OF GUIDELINE VALIDATION

Peer Review

# **DESCRIPTION OF METHOD OF GUIDELINE VALIDATION**

The guidelines were validated according to the European Federation of Neurological Societies (EFNS) criteria (see "Availability of Companion Documents" field).

## RECOMMENDATIONS

#### MAJOR RECOMMENDATIONS

The levels of evidence (class I-IV) supporting the recommendations and ratings of recommendations (A-C, Good Practice Points) are defined at the end of the "Major Recommendations" field.

## **Diagnostic Criteria**

The Task Force suggests that the criteria for post-polio syndrome (PPS) used within European Federation of Neurological Societies (EFNS) and Europe should be based on the Halstead's definition from 1991 with emphasis on the new muscle weakness (refer to the original guideline document for details). The diagnosis of PPS is an exclusion diagnosis with no test or analysis specific for PPS, and the role of the investigation is to rule out every other possible cause for the new symptoms and clinical deterioration.

## **Therapeutic Interventions**

#### **Level A Recommendations**

A small number of controlled studies of potential specific treatments for PPS have been completed, but no definitive therapeutic effect has been reported for the agents evaluated (pyridostigmine, steroids and amantadine).

#### **Level B Recommendations**

Supervised muscular training, both isokinetic and isometric, is a safe and effective way to prevent further decline of muscle strength in slightly or moderately weak muscle groups and can even reduce symptoms of muscular fatigue, muscle weakness and pain in selected post-polio patients. There are no studies evaluating the effect of muscular training in patients with severe weakness and the long-term effects of such training are not yet explored. Precautions to avoid muscular overuse should be taken with intermittent breaks, periods of rest between series of exercises and submaximal work load.

Training in a warm climate and non-swimming water exercises are particularly useful.

#### **Level C Recommendations**

Recognition of respiratory impairment and early introduction of non-invasive ventilatory aids prevent or delay further respiratory decline and the need of invasive respiratory aids.

Respiratory muscle training can improve pulmonary function.

Group training, regular follow-ups and patient education are useful for the patients' mental status and well-being.

#### **Good Practice Points**

Weight loss and adjustment and introduction of properly fitted assistive devices; but lack significant scientific evidence.

## **Definitions:**

## **Evidence Classification Scheme for a Diagnostic Measure**

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# **Evidence Classification Scheme for a Therapeutic Intervention**

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**Good Practice Points** When only class IV evidence was available but consensus could be reached the Task Force gives recommendations as good practice points.

# CLINICAL ALGORITHM(S)

None provided

# **EVIDENCE SUPPORTING THE RECOMMENDATIONS**

#### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for selected recommendations (see "Major Recommendations" field).

# BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

#### **POTENTIAL BENEFITS**

Appropriate diagnosis and treatment of post-polio syndrome (PPS)

## **POTENTIAL HARMS**

Precautions to avoid muscular overuse while exercising should be taken with intermittent breaks, periods of rest between series of exercises and submaximal work load.

## **QUALIFYING STATEMENTS**

# **QUALIFYING STATEMENTS**

This guideline provides the view of an expert task force appointed by the Scientific Committee of the European Federation of Neurological Societies (EFNS). It represents a peer-reviewed statement of minimum desirable standards for the guidance of practice based on the best available evidence. It is not intended to have legally binding implications in individual cases.

## **IMPLEMENTATION OF THE GUIDELINE**

## **DESCRIPTION OF IMPLEMENTATION STRATEGY**

The European Federation of Neurological Societies has a mailing list and all guideline papers go to national societies, national ministries of health, World Health Organisation, European Union, and a number of other destinations. Corporate support is recruited to buy large numbers of reprints of the guideline papers and permission is given to sponsoring companies to distribute the guideline papers from their commercial channels, provided there is no advertising attached.

#### **IMPLEMENTATION TOOLS**

Staff Training/Competency Material

For information about <u>availability</u>, see the "Availability of Companion Documents" and "Patient Resources" fields below.

# INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

## **IOM CARE NEED**

Getting Better Living with Illness

## **IOM DOMAIN**

Effectiveness Patient-centeredness

# **IDENTIFYING INFORMATION AND AVAILABILITY**

## **BIBLIOGRAPHIC SOURCE(S)**

Farbu E, Gilhus NE, Barnes MP, Borg K, de Visser M, Driessen A, Howard R, Nollet F, Opara J, Stalberg E. EFNS guideline on diagnosis and management of post-polio

syndrome. Report of an EFNS task force. Eur J Neurol 2006 Aug;13(8):795-801. [80 references] <u>PubMed</u>

## **ADAPTATION**

Not applicable: The guideline was not adapted from another source.

## **DATE RELEASED**

2006 Aug

# **GUIDELINE DEVELOPER(S)**

European Federation of Neurological Societies - Medical Specialty Society

## **SOURCE(S) OF FUNDING**

European Federation of Neurological Societies

## **GUIDELINE COMMITTEE**

European Federation of Neurological Societies Task Force on the Diagnosis and Management of Post-Polio Syndrome

## **COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE**

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## FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

The authors have reported no conflicts of interests.

## **GUIDELINE STATUS**

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#### **GUIDELINE AVAILABILITY**

Electronic copies: Available to registered users from the <u>European Federation of</u> Neurological Societies Web site.

Print copies: Available from E. Farbu, Department of Neurology, Stavanger University Hospital, N-4068 Stavanger, Norway; Phone: +47 5151 8447; Fax: +47 5151 9916; E-mail: <a href="mailto:elfa@sir.no">elfa@sir.no</a>

## **AVAILABILITY OF COMPANION DOCUMENTS**

The following are available:

- Brainin M, Barnes M, Baron JC, Gilhus NE, Hughes R, Selmaj K, Waldemar G; Guideline Standards Subcommittee of the EFNS Scientific Committee.
  Guidance for the preparation of neurological management guidelines by EFNS scientific task forces revised recommendations 2004. Eur J Neurol. 2004 Sep;11(9):577-81. Electronic copies: Available in Portable Document Format (PDF) from the European Federation of Neurological Societies Web site.
- Guideline papers. European Federation of Neurological Societies. Electronic copies: Available from the <u>European Federation of Neurological Societies Web</u> site.
- Continuing Medical Education questions available from the <u>European Journal</u> of Neurology Web site.

#### **PATIENT RESOURCES**

None available

## **NGC STATUS**

This NGC summary was completed by ECRI on April 9, 2007. The information was verified by the guideline developer on May 15, 2007.

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